SO I HAVE A CYSTIC FIBROSIS GENE, BUT WE CAN'T TEST MY PARTNER

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You have had a cystic fibrosis (CF) carrier test that showed you are a carrier. But, we can't test your partner. Now what?

How do you know I am a carrier for CF?

The blood test looked for the most common changes in the pair of CF genes. Since you have one of the common changes in one of those genes, you are a carrier.

What is a carrier?

A carrier is someone who has one changed gene (mutation) for the disease CF. Genes do not change during one's lifetime, so a carrier will always be a carrier, but will never get sick with CF. Carriers do not need any special medical care. People with CF always have two changed genes.

What is CF?

CF is a disease that causes breathing and digestion problems. Symptoms usually begin in the first year of life and get worse over time. Some children are very sick; others are not. Problems may include coughing, repeated pneumonia, lung damage, diarrhea and poor growth. People with CF are not mentally retarded. Their appearance is not affected. Life is usually shortened, but most children with CF live 20 to 35 years. There is no cure. Treatment is usually medicine and physical therapy.

What is the chance I will have a baby with CF?

Two things have to happen for you to have a child with CF.

First, both you and your partner must be carriers. Then, the baby must inherit the changed CF gene from both you and your partner. When it is known that both parents are carriers, the chance that the baby will be affected is 1 in 4 (25%).

Since we do not know if your partner is a carrier, we can only guess whether your baby will have CF. The chance that your baby has CF is at most 1 in 4 (25%). There is at least a 3 in 4 chance (75%) that your baby does not have CF. Your health care provider or a genetic counselor can figure out your own chance.

What is the chance my partner is a carrier?

The chance depends on your partner's race (or ethnic group). His chance of being a carrier is highest if he is white. Your health care provider or a genetic counselor can figure out his chance.

Should I have the baby tested during pregnancy?

Since we don't know if your partner is a carrier, the test during pregnancy is not very accurate. You should talk to a genetic counselor to fully understand what the test on the baby could tell you, as well as the chance the test could cause a problem in your pregnancy.

Can the baby be tested after birth?

Yes. After a few months, a baby can be tested for CF.

Should I tell other people in my family?

Since you are a carrier for CF, other people in your family may be too. You could suggest they talk to their health care provider or a genetic counselor to see if they want to be tested.

How can I get more information? How can I decide what to do?

Talk to your health care provider or see a genetics specialist, a genetic counselor. A genetic counselor is specially trained to help you decide what is best for you. A genetic counselor will answer your questions about the blood test results, the testing you could have in the pregnancy and answer any other questions you have about CF.

This fact sheet was written by the PacNoRGG (Pacific Northwest Regional Genetics Group) Education and Prenatal Genetics committees and is consistent with the 2001 Clinical and Laboratory Guidelines, *Preconception and Prenatal Carrier Screening for Cystic Fibrosis*, published by the American College of Obstetricians and Gynecologists and the American College of Medical Genetics. More detailed patient brochures, *Cystic Fibrosis Carrier Testing: The Decision is Yours,* and *Cystic Fibrosis Testing: What Happens If Both My Partner and I Are Carriers?* can be purchased from ACOG, www.acog.org; (202)863-2518.

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This brochure is available on the PacNoRGG web site:
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